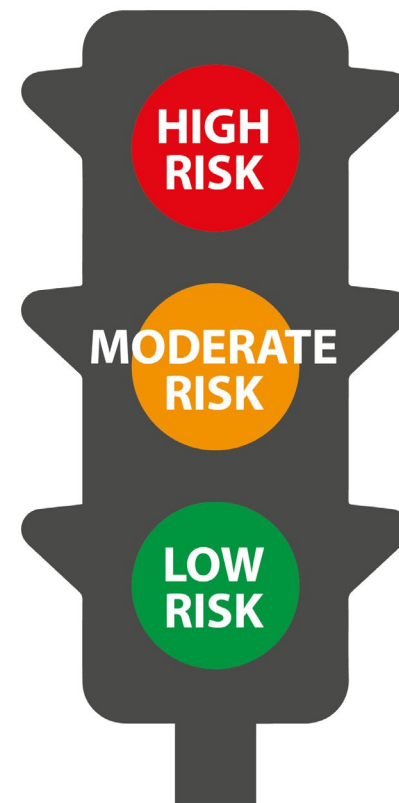


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Safe Patient Selection for PEG in MND - MND gastrostomy pathway development

Safety and Quality First 

- 
- Dysphagia occurs in more than 80% of people living with MND as the disease progresses. ^{1,2}
 - Respiratory muscle weakness eventually affects most people with MND with ventilatory failure being the most common cause of death.³
 - 2017 MND patient suffered a near death due to intra-procedural respiratory arrest during gastrostomy insertion at FHN



Exploring clinical experience/practice

2013 MND International Symposium – Oxford MND Care Centre presented traffic light approach to assessing respiratory risk to guide decision making

The Grampian Collaborative Pathway 2015/16– traffic light system that risk stratifies MND patients

Cambridge team adopted nasal unseated seated PEG technique for patients with respiratory compromise. Published data 2017



Evidence

ProGAS 2015 ⁽⁴⁾

30 day mortality rate independent of gastrostomy method
PEG, PEG, RIG as safe as each other

↑ 30 day mortality risk & ↓ mean survival if >10% weight loss at insertion

Threshold to recommend gastrostomy 5% weight loss

MND Nice Guidelines 2016 ⁽⁵⁾

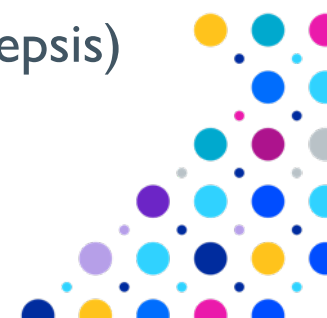
Discuss gastrostomy at an early stage & at regular intervals
Explain benefits of early & risk of late placement

Respiratory function tests at diagnosis & then every 2-3 months

- SpO₂
- FVC
- SNIP
- Arterial or capillary blood gases

2017/18 - Retrospective review of outcomes of patients with MND undergoing gastrostomy insertion at JCUH

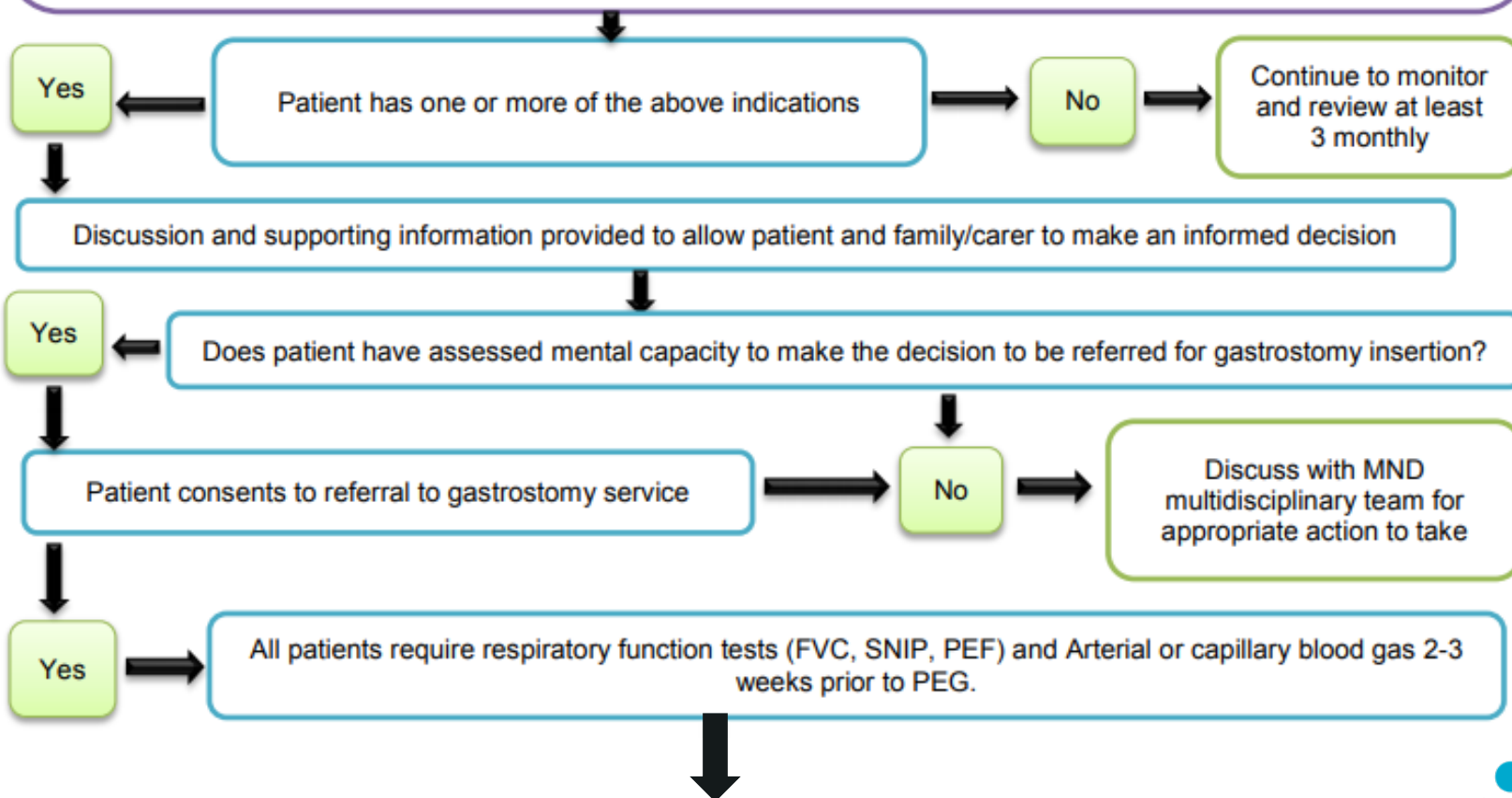
- 2 year case series – 35 patients identified (Jan 2016-Nov 2017).
- Respiratory complications 5/35 (14%) cases
 - 1 respiratory arrest
 - 2 desaturated – unsafe to proceed
 - 2 desaturated but still possible to place gastrostomy
- 14% were using NIV prior to procedure with no specific peri-procedural plan.
- Mortality
 - At 7 days 0%
 - At 30 days 9 % (2 pts with pneumonia, 1 pt with urinary sepsis)



Middlesbrough MND Care Centre - Assessment for gastrostomy tube placement in MND patients

MND gastrostomy indications

- 5% weight loss from weight at diagnosis
- Signs of respiratory impairment
- Recurrent chest infections
- Upper limb weakness and physical feeding difficulties
- Cognitive changes
- BMI of 20 or less
- Reduced oral intake
- Prolonged meal times
- Bulbar symptoms – Dysphagia, dysarthria, poor secretion management



Using the traffic light system below, identify which route is appropriate and refer to gastrostomy service, identifying patient's level of risk

Low risk (Green)

- No respiratory symptoms or fatigue
- Poor appetite
- Less than 5% weight loss
- Poor speech volume

Moderate risk (Amber)

- More than 5% weight loss with no associated respiratory symptoms
- Morning headache
- Orthopnoea
- Shallow breathing
- Non-refreshing sleep
- Breathlessness
- Disturbed sleep
- Daytime sleepiness
- Use of accessory muscles of respiration
- Increased respiratory rate
- Established non-invasive ventilation (NIV)
- Sniff Nasal Inspiratory Pressure (SNIP) > 40cmH₂O
- Forced Vital Capacity (FVC) > 50% of predicted value
- FVC fall less than 15% on lying flat
- SpO₂ equal or more than 94% (without known lung disease) or 92% (with known lung disease)
- Can lay flat for 20 minutes

High risk* (Red)

- More than 10% weight loss with associated respiratory symptoms
- Poor concentration and/or memory
- Confusion
- Hallucinations and/or nightmares
- Recurrent chest infections
- Abdominal paradox
- Reduced chest expansion on maximal inspiration
- New to non-invasive ventilation/unable to tolerate Non-invasive ventilation
- SNIFF Nasal Inspiratory Pressure (SNIP) <40cmH₂O
- Forced Vital Capacity (FVC) <50 of predicted value
- Unable to lay flat for 20 minutes or more

*All high risk patients require assessment by a respiratory consultant/physician.

All MND PEG referrals to be discussed at the weekly PEG MDT & will receive a PEG pre-assessment appointment

Low risk (Green)

- Gastrostomy may go ahead on a routine list.
- Continue to monitor and if there is a delay of more than 6 weeks, re-evaluate in MND MDT

Moderate risk (Amber)

- Gastrostomy to go ahead on a dedicated consultant list experienced in the care of patients with potential respiratory compromise.
- If appropriate, non-invasive ventilation must be available during & post procedure.
- If there is a delay of more than 3-4 weeks, re-evaluate in MND MDT

High risk* (Red)

- Push gastrostomy to be inserted via trans-nasal endoscopy (TNE) in a seated position with no sedation, on a dedicated consultant list experienced in the care of patients with potential respiratory compromise.
- MND Specialist Nurse to be present during the procedure.
- If appropriate non-invasive ventilation must be available during & post procedure.
- If there is a delay of more than 3 weeks, re-evaluate in MND MDT.

All high-risk patients

- To be admitted the night before procedure to Neurology (ward 27 JCUH) and the appropriate gastrostomy care pathway followed.
- Consider discussion with consultant anaesthetist and/or home ventilation team for advice on respiratory support / HDU admission post-procedure.

Moderate risk patients established on NIV

- To be admitted / have a guaranteed bed on Neurology (ward 27 JCUH) post procedure.

All patients:

- To remain an inpatient for at least 24 hours, post procedure.
- To be reviewed via dietitian during admission. For SALT review if appropriate.
- To receive PEG nurse review / senior medical review within first 48 hours or prior to discharge if <48 hours.

Follow up:

- All patients to receive dietetic follow up via MND Clinic, if able to attend or local dietetic service.
- All patients to receive a PEG review appointment in Endoscopy Department, if able to attend, within 3-6 months of discharge from hospital.

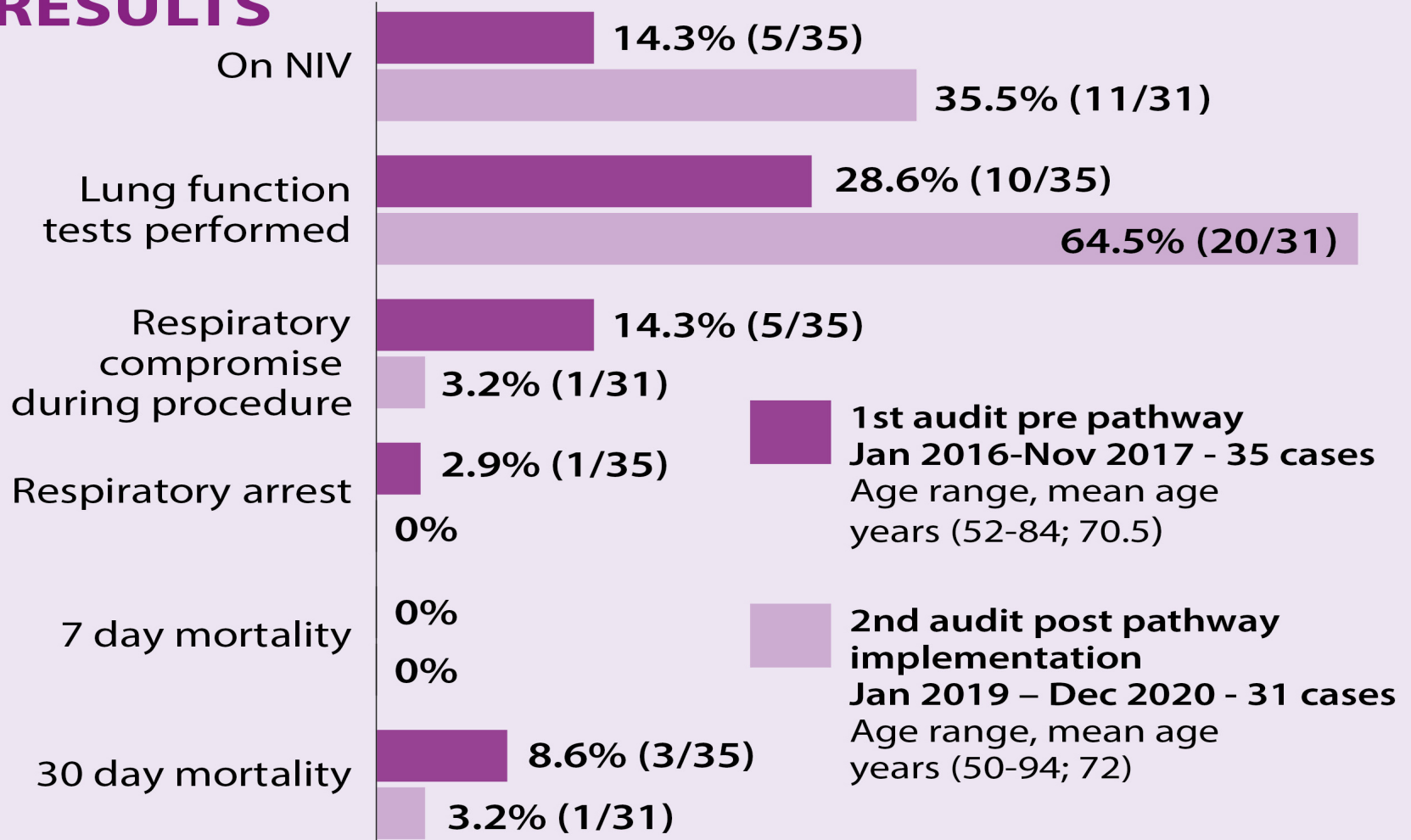
Please consider the following if sedating an individual with Motor Neurone Disease:

- If established on NIV this should be used during the endoscopy (nasal mask for endoscopic procedure or full face mask for TNE procedure).
- For endoscopic pull gastrostomy placement throat spray should not be used as this can potentially increase the risk of aspiration and minimal sedation is normally required with midazolam. Fentanyl should not be required.
- Desaturation may occur in this patient group when lying flat, therefore a trial of lying flat unsedated for 5 minutes whilst monitoring using a saturation probe is recommended.
- If oxygen saturations fall then it may be necessary to sit the patient up slightly and repeat the above step.
- If saturations are stable you can proceed with sedation. A suggested dose of midazolam is 0.5 - 1mg initially and observing for a further 5 minutes.
- Midazolam's peak onset of action is at 3-6 minutes; therefore it is necessary to wait an appropriate time before assessing whether more is required.
- MND patients with respiratory involvement (or those with NIV) an acceptable oxygen saturation range would be 88-92%. For those without known respiratory involvement, an acceptable oxygen saturation range is 92-94% as per NICE MND and BTS oxygen (in neuromuscular patients) guidelines.
- Depending on level of sedation & O2 saturations you can either proceed with procedure or give further sedation. It is suggested that no more than 0.5mg increments of midazolam is given at a time.
- If a minimally sedated patient is not tolerant of intubation you can try rotating them onto their side for intubation then rotating back onto their back for the gastrostomy insertion.



Results - Retrospective review of all patients (MND) undergoing gastrostomy comparing outcomes pre and post pathway implementation

RESULTS



Further resources

- <https://www.rcnevents.tv/>
 - Annual Stephen Hawking Lecture November 2020 – Respiratory Care in MND patients by Dr Ronan Astin – Consultant in Adult Ventilation Medicine UCLH
- <http://mytube.mymnd.org.uk/>
- <https://mybreathing.mymnd.org.uk/>
- <https://www.mndassociation.org/professionals/publications/>
- <https://www.mndassociation.org/support-and-information/information-resources/information-for-people-with-or-affected-by-mnd/>





References

1. Tomik, B. and R.J. Guilloff, Dysarthria in amyotrophic lateral sclerosis: A review. *Amyotrophic Lateral Sclerosis*, 2010; 11(1-2): 4-15
2. Muscaritoli M, Kushta I, Molfino A, Inghilleri M, Sabatelli M, Rossi Fanelli F. Nutritional and metabolic support in patients with amyotrophic lateral sclerosis. *Nutrition* 2012; 28(10): 959–966
3. Radunovic A et al. *Mechanical ventilation for amyotrophic lateral sclerosis/motor neuron disease*. Cochrane Database of Systematic Reviews 2013.
4. ProGas Study G (2015) Gastrostomy in patients with amyotrophic lateral sclerosis (ProGas): a prospective cohort study. *Lancet Neurol.* 14: 702-709.
5. National Institute for health and Clinical Excellence (NICE) (Feb 2016) Motor neurone disease: assessment and management. London. NICE. NG42
6. McCulloch A et al. Nasal unsedated seated percutaneous endoscopic gastrostomy (nuPEG): a safe and effective technique for percutaneous endoscopic gastrostomy placement in high- risk candidates. *Frontline Gastroenterology* 2017; (0)1-5





THANK YOU